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Dissemination of Prostate Cancer Screening to PCP's in African American Communities, PC020492

INTRODUCTION. The aims of this project are to adapt and extend the use of academic detailing to the dissemination of prostate cancer (CaP) screening findings to primary care physicians practicing in African American communities. *The objectives of this study are:*

1. **To test the hypothesis that a community physician-based educational intervention (multi-component academic detailing, including an interactive, digitized, web-based program for informed decision-making about prostate cancer, and patient education materials designed for low literacy patients) will increase physician knowledge, positive attitudes/beliefs toward screening and screening options, and prostate cancer screening (using the digital rectal exam, and the serum prostate specific antigen test) at baseline, 6-, and 12-months post- randomization, compared to the rate observed in a service- as-usual control.**
 - 1A. **To demonstrate the feasibility of disseminating the American Cancer Society guidelines for prostate cancer screening among primary care practitioners using multi-component academic detailing.**
2. **To develop models predicting which physician offices are most and least likely to adopt the intervention, and to generate hypotheses about tailoring the dissemination of PC screening guidelines to different physician subgroups.**

The long term goal of this project is to increase prostate cancer screening among African American communities, thus decreasing cancer-related morbidity and mortality.

BODY.

The Focus Groups: Pilot Test Phase. Through the connections established by Drs. Ashford and Lantigua with St Barnabas Hospital in the Bronx (Drs. Rosing and David Fox), and Downstate Medical Center in Brooklyn (through Dr. Allen Chen), who are members of our physician advisory board, we have recruited 15 primary care physicians, their patients, and other similar community residents (N=76) to; 1) refine the behavioral intervention; and 2) ensure that all key variables are assessed and are culturally sensitive and relevant (IRB-approved protocols are approved at our institutions). The physician focus groups were guided by our semi-structured protocol, with open-ended questions concerning their knowledge of, barriers to, supports for, and conduct of PC screening in the local community. The patient focus groups were guided by an adapted protocol developed and tested by CDC (unpublished manuscript) and ¹, using the Health Belief Model. The patient focus groups provided open-ended feedback concerning the length, quality, and completeness of the intervention, and assisted some with back translation². Rather than conduct six focus groups (2, physician, 4, patient) during the first 6 months of the study, as we had planned, we have run the focus groups during year 2 of the study. All interviews have been transcribed for content analysis

(CA).¹ In the analyses, we have used the SPSS Text-smart program to search for consistent themes.

Results

Since our receipt of IRB and administrative approval for phase I of the study, on March 29, 2004, we have conducted 11 patient focus groups (N=76). Men were recruited from a range of community organizations, 5 senior centers, YMCA Transitional Housing Project, Salvation Army Center, and a "Master Barber" workshop for men who are homeless that was held at a local church, as well as a focus group for air traffic controllers held at the Newark airport.

Seventy one percent of the men in the groups were Black/African American; 71% of the group members were between the ages of 45 –75. Two-thirds of the men (66%) were in the low income category (<\$15,000); 55% had reported taking a PSA test and 87% had health insurance coverage.

The findings are summarized by CaP screening knowledge, general attitudes/beliefs about cancer and early detection, barriers or supports to the screening decision, and the role of the physician in the decision-making process.

Knowledge of CaP and screening

In every group at least one person asked for an explanation about the prostate and prostate cancer. One man expressed very eloquently how little he knew about the prostate:

"I never knew where the prostate was until they started talking about it, what maybe 5, 6 years, everyone's talking about it, but I never knew..... if you asked me where my prostate was I couldn't tell you. And right now if you ask me I could tell you I think it's in the back of my neck! Right now I do know from listening and reading that it's in the groin area, you know, where at? Don't ask me! I really don't know where exactly its at.....I have an idea you know in the area, what it is and what function it does.. I don't even know that for real. I think it has something to do with your sperm...."

In most of the groups a man asked a specific question to clarify whether it affected both men and women. In all of the groups most of the men struggled with defining or describing prostate cancer. Expressions like "you have it in the upper or lower part" and "its like a sore inside the groin," "it attacks the gall bladder," "it's an enlargement of the band in the rectum" exemplify this. There were many references associating prostate cancer with "enlargement" and "rectum" in the group discussions and a few references to impotence: "losing the manly functions, men have heard about that"

Colorectal cancer and colonoscopy were confused with prostate cancer and prostate cancer screening in nearly every group discussion.

In all of the groups there were misunderstandings about the nature and purpose of the two prostate cancer screening tests (PSA and DRE) and very few of the group members recognized the name PSA (or Prostate Specific Antigen) or knew that it was a blood test. As a result, men generally had little to say about the PSA test. Among those who knew what it was, the PSA test was compared to HIV surveillance: "The same with HIV, you gotta keep your count down"

Nonetheless, there was at least one man in each group who had experienced difficulties with his prostate or who knew someone with prostate difficulties; these individuals were most familiar with PSA terminology and screening tests. Generally, they shared their knowledge about prostate cancer with the rest of the group.

The DRE was familiar to most group members as evidenced by their comments; the test was dubbed nicknames such as "the pain test," "finger test," "the probe," and "the man test." For some men, the PSA was seen as a more favorable alternative to the DRE.

Confusion about the names, procedures, and purpose of the specific tests for prostate cancer was compounded by more general misunderstandings about many of the terms used in a medical encounter such as blood work, screening, and check-ups.

General attitude toward/beliefs about cancer and early detection

As at least one man in every group had an experience with cancer, moving personal experiences were expressed in every group. As one man described it:

"I would imagine that everyone in here has a friend or knows of someone who unfortunately had it or has it and are still alive and are going through the treatment, you know or have unfortunately passed away...."

As a result, themes of bodily deterioration, pain and death were common in the group discussions. One man stated that:

"Its horrible to see someone you care about who is literally deteriorating in front of you and there's nothing you can do, literally nothing, you just stand there and watch them deteriorating and dying .."

These general attitudes and beliefs toward cancer contextualized specific fears about CaP and CaP screening. One man succinctly described the common fear of the debilitating effects of cancer:

"Its pretty much not so much the fear of dying, because we're all going to die, it's the fear of having someone bring you water, of being so weak that I need someone to care for meits fear of losing my self respect and dignity and being helpless."

Equally common was the view that if the cancer was detected early enough then the outcome was more positive.

“It depends if you catch it in time and if you don’t bother to go see about it, it will spread and go to other parts, the key is to catch it in time and see the doctor to see about it.”

“If you catch it in time, like me if you catch it in time you can treat it, but if you wait ‘til it gets out of hand there’s nothing you can do “

“Now science has come up with something that can just about cure it now. Before they found anything it was a deadly weapon for people who got it, but now they have something that can stop it, cure it, or prolong life.”

Barriers to screening

As we have uncovered in our other studies of cancer screening in this community, ³ fear is a key barrier to early detection. Men cited their fear of losing control over any treatment, disfigurement, being “experimented on.” One man stated:

“I’m afraid they’re going to find something wrong with you. If you don’t have the fear you don’t mind going, and when you do have the fear and go sometimes, it’s too late.”

In particular, men reported a fear of tests causing pain or discomfort.

About the PSA: “A man is silly sometimes, they hate to go for that testing, that screening, when they take a little blood out of their arm you hear them hollering and screaming, they hate these things you know.”

“ For me I’ve got a needle phobia”

Less adaptive coping mechanisms, such as avoidance and alcohol consumption, were used to cope with fear.

“ Sometimes they know their symptoms but they start drinking, then they don’t feel sick. After their drinking the symptoms die down and they do that for a long time ‘til they have to go to the doctor.”

Men identified other priorities as keeping them (or other men like them) from screening:

"I have to go to work today. They keep putting it off."

Some men cited the risk of embarrassment from disclosing positive test findings to others; this was not a concern that was expressed across all of the groups, however.

"...There might be an embarrassing moment is the only risk there is, and that embarrassing moment you don't have to tell people is the only risk. It's something that you should be able to do, so there's no risk. Forget about the risk."

Men in each group reported that the test makes men look "less manly." In several groups held since our last report, we were able to further elaborate this concept. Men tended to associate the rectal examination in particular with sexual behavior. The DRE seemed to undermine heterosexual notions of manhood, and to tap an undercurrent of "homophobia." The PSA, as a blood test not involving rectal insertions, was not similarly "undignified." As one man expressed:

"Yes, I think it's [prostate cancer screening with the DRE] all about...maybe for some men it's a homophobia. I think that's the issue here. But I think with the PSA test I think that's helped a lot of men there, I think it's saved a lot of lives, they don't have to do the rectal exam."

Expectations for screening (as well as the heterosexual male role) were reinforced or diminished by social networks. Lack of support for screening from salient member of social network reduced the likelihood that men would screen for CaP. Social networks provided information (or misinformation), barriers to or supports for screening, and the potential for social isolation if cancer is diagnosed.

"Misinformation and some people make it worse than it is, its not really going to hurt that bad. The truth of the matter is it ain't going to kill you"

"And then there's some people like myself, they live alone and they got nobody to look after them so they just don't go"

"A lot of people treat you a different way because you have cancer, they don't want you bothering them."

Cancer-related social isolation also increases the risk of psychological distress in embarrassment, depression, and, in the most extreme cases, suicidal thoughts.

"Well you know, first its knowing you got it, then once you have it it's the treatment, the repercussions you know, loss of weight, it's the psychological thing, also, not only for you but for your loved ones, and that whole thing"

“Depression....and say hey forget about it and say you’re not going to do anything about it, you know, people give up, you know they give up, with all you have to deal with socially, financially, you know, it’s a lot. And then comes the isolation, people treating you as if you’re a leper or whatever, you know what I’m saying? The look, the stares, the sympathy, you know it’s a lot. You don’t want these things...”

“A lot of people treat you a different way because you have cancer, they don’t want you bothering them”

“Cause a lot of people are disturbed and lock themselves in and no one knows these things, they separate themselves from their own people”

As has been uncovered in numerous studies of cancer prevention and control,³ a lack of symptoms reduces early detection.

“It’s like having a toothache, you don’t go to the dentist until you feel pain. It’s the same with the prostate, you don’t feel nothing, you don’t worry”.

A barrier that patients share with physicians is that the test may not be accurate.

“What’s the best way to detect prostate cancer? I would say it’s the PSA test. Recently there has been reservations about that because it’s not so accurate”

Benefits of Screening

Few benefits of screening were mentioned across all of the groups. The most common advantage from most of the groups was “peace of mind” if the test was negative. One man stated that, if the test is negative, “...it kind of makes it easier for you to go testing again.”

There was a consensus across the groups that early detection promotes positive outcome, particularly in individuals at familial risk for CaP.

“One reason for screening is to...detect if it runs in the family, and if you detect CaP early then there’s a better chance of treating it.”

“One thing about cancer, my dad had cancer and I’m at high risk, you know what I’m saying, I make sure I get checked, I’m careful, I keep up with my check ups.”

“Hey ya’ll this is like first hand...because my Dad had it (prostate cancer), and he had an operation and had it cut out, so I have been having the tests (PSA and DRE) since my early 30’s”.

Even with the DRE, that posed a potential threat to the man's sense of his manhood and was not comfortable, men expressed the view that they were "a necessary evil," as expressed by one man:

"I understand that is a little painful when they do the exam, (DRE) when they have the probe, and you know me, I'm not with that, you know what I'm saying, but have to do whatever it takes, you know" .

Although lack of health insurance coverage is a central barrier to cancer screening,⁴ since many of the participants in these groups had coverage, this factor was generally expressed as a support for screening.

"What really connected the dots for me was when I was forty and I got my Medicaid card."

"Because up until 2003 I didn't know. My mom told me. And then when I got into this program I found out, when I'm on Medicaid and everything and I started to think twice about certain things and got the chance to do something when I hadn't had the chance to do before. Hey I'm basically a healthy person, but that's one of the reasons I put it off, not having the right health care.

Countering men's fears of having prostate cancer was suggested by some of the groups as a way to encourage screening. In particular, several men felt that having information about treatments that would protect sexual functioning would encourage screening, as follows:

"So, what you get to learn about some of these things that are going on and how new instruments and new ideas have been implemented, and have one that still functions maybe the fear factor settles down a little "

Role of the physician in the decision-making process

Importantly, among this generally insured group of men, with access to health care, there was a sense of confidence in the provider to monitor their health and administer preventive care, as needed.

"So that's why you need to go to the doctor at least twice a year to avoid anything that might happen to you, to catch it early when it's beatable, if you leave it too late it's unbeatable."

Despite the central role that the physician plays in the decision to screen, particularly as a trusted source of information, many men suggested that physicians were not always prevention-oriented. As has been suggested in a number of studies^{5, 6} these urban offices are often extremely busy, and physicians practicing in medically underserved areas have limited time and office-based resources for prevention. As one man stated:

"I think that's one of the issues sometimes, with doctors that we have, doctors treat, they don't a lot of times give you any prevention advice."

Finally, some men indicated that their physicians' diagnoses were confusing to them, leaving them with uncertainty about their prognoses, and perhaps fear.

"Some people may have an enlarged prostate, ...but ...they don't understand what an enlarged prostate means, they say [they] have prostate cancer.

The process of reporting back to one's personal physician was described as a powerful incentive to go for screening, as described in the following:

"...and the only reason I did go was because I had to go for another annual examination by the doctor and I didn't want him to say well I asked you to go and then , you know for a whole year you didn't go, so that drove me to go"

A common explanation given by group members for annual prostate cancer screening was that it was part of their routine medical check up administered by their physician.

Discussion

Overall, there was low awareness of CaP and screening, and some misinformation. This finding suggests the importance of increased patient education using print, video, digital media (review in ⁷). As the physician is a particularly trusted source of screening information for prostate cancer, and prevention information is not always either forthcoming or accurate, s/he is an important target for intervention. Increased discussion of both prostate cancer screening and treatment by the health care provider with the patient is warranted, with clear, simple language appropriate to a lay person, accompanied by low literacy health education materials.

Generally, the risks of cancer seem better known among African American men than benefits of CaP testing. This finding highlights the importance of additional discussions between providers and patients about the supports for screening, particularly among those at higher medical risk. Further, given the importance of social networks and the informal information sources that they provide, as well as their expectations for screening, network-based educational approaches may be beneficial, such as those conducted among first degree relatives of African American women who have been diagnosed with breast cancer. ⁸

There are no provider-based models of informed decision-making for CaP screening, although several patient-based video and print materials have been developed, and digital approaches are near-completion. Given the importance of the provider in preventive medicine, the testing of office-based intervention models, as proposed in this study, is a next step.

CD ROM and web-based physician education materials (see figures 1 and 2).

In addition to conducting the 11 patient focus groups, and the physician discussions, over the past two years, as a result of our review of the published literature, we have nearly completed our testing of a model for the web-based CD-ROM that will be composed of a series of 4 professionally scripted scenarios, with patients in different prostate cancer risk categories, three African American or Hispanic (including African, Afro-Caribbean, and African-American) and one white man. *We have presented our preliminary findings to an international informatics conference on prostate cancer.*⁹ Each case explores the risks and benefits of screening, screening options or alternatives, and models the process of values clarification and mutual decision-making. With the use of a branching structure, physicians receive feedback on the suitability of their responses according to professional guidelines and our expert advisory panel. Throughout, *as we have done in our development of a CD-ROM for colorectal cancer prevention and screening*, we are including adjunct text, digitized images (e.g., of a core needle biopsy), medical illustrations, and pathology slides to illuminate our primary aims¹⁰. Once the CD-ROM is connected to the web, sites for downloading these materials will also become accessible, for frequent updating. CME credits will be offered to all physicians who successfully complete the post-tests on these materials.

As in our previous projects, we have been working alongside Ms. Yalini Sen, an informatics colleague, as well as two web design consultants with whom we successfully produced our earlier CD-ROM that was designed to assist primary care providers to appropriately recommend colorectal cancer screening.

We have continued to experience several major delays in the conduct of our project, particularly from the HSRRB, although we anticipate that, now (MFR dated 13 April 2005) that we have received our approval for Phase II among 90% of the primary care physicians who are covered by the Teachers College Columbia University or Columbia University Medical Center IRB's, we will rapidly make up for the lost time. With our continued extensive development of the CD-ROM, in particular, and our continued updating of the scientific underpinnings of the project, we anticipate successfully completing the project in a timely manner. Further, as a result of the 31 March meeting led by Dr. Mishra, we have also received approval for the receipt of the project funds to Teachers College Columbia University.

KEY RESEARCH ACCOMPLISHMENTS. We have updated an informative review of the effectiveness of digital decision-making tools for informed decision-making in prostate cancer screening. We are completing a model for the interactive, digital, web-accessible CD-ROM. We have completed a series of focus groups to inform the development of Phase II, the randomized clinical trial.

REPORTABLE OUTCOMES. We have presented one poster to an international conference on prostate cancer informatics.

CONCLUSIONS. We have completed our pilot phase, and have received final HSRRB approval for phase II of the study among the 90% of primary care physicians

who are covered by the Teachers College Columbia University or the Columbia University Medical Center IRB's, as well as the transfer of funds to Teachers College Columbia University. We anticipate successfully completing the study on time, despite the delays.

Figure 1. Digital Detailing: page one

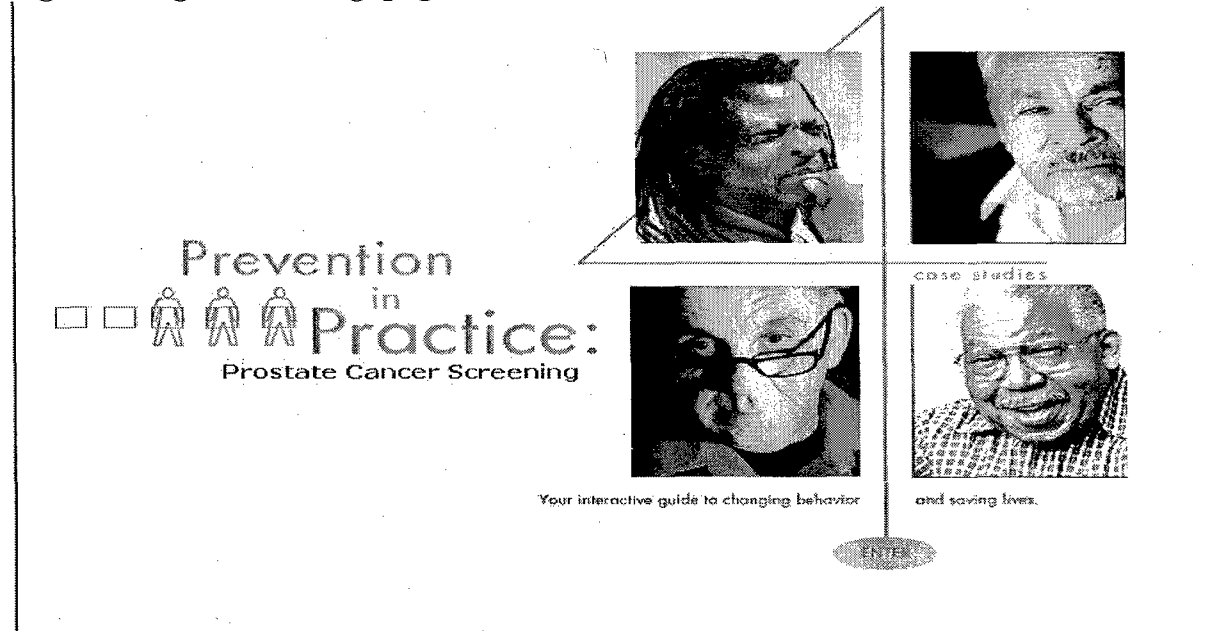


Figure 2. Digital Detailing: Patient query.



Prevention in Practice:
Prostate Cancer Screening

home introduction supporting materials related resources help contact us

James Howard scene 1

profile

What is the best response to Mr. Johnson's question?

SUPPORTING MATERIALS  
Mouse over an arrow to scroll the list.
Click an item to view it.

- Summary of Reasons to Screen

QUESTION:

Hi Doctor. I'm here today because I'm a little worried. I just found out my cousin has prostate cancer, which scared me because he's only 56 and has always been healthy. I never miss my annual checkups, and I've had other tests every year since I turned 40. But I'm already 51 and I haven't been checked for prostate cancer. Should I be concerned?

How would you respond to Mr. Johnson's question?

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